



Appendix 1

What do patients and carers want from online access to GP (Primary Care) records?

Participant Information Sheet (PIS)

You are being invited to take part in a research study to find out more about what patients and carers want from online access to GP (Primary Care) records. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

About the research

➤ Who will conduct the research?

Dr Brian McMillan, Prof Caroline Sanders and Dr Gail Davidge (Division of Population Health, Health Services Research and Primary Care, School of Health Sciences, University of Manchester) in collaboration with Dr Helen Atherton (Warwick Medical School, University of Warwick) and Dr Freda Mold (School of Health Sciences, University of Surrey).

➤ What is the purpose of the research?

‘Online access’ refers to patients and their carers being able to access their GP record (or the record of the person they care for) online. Research shows benefits of online access to records, for example, people feel more in control and more able to communicate with healthcare staff. The down sides include some professionals not being keen on the idea, people worrying about how secure this is, or not always understanding what is in their record.

Research has mainly looked at the pros and cons of online access, or at how people look at their record. More research is needed to find out how to design patient records to support people to stay healthier for longer. For people to get the most out of being able to see their health record (or the record of the person they care for) online, we need to understand more about what people actually want from online access to records.

The study asks: What do people want from online access to their GP record (or the record of the person they care for), what would they like to be able to do with this, and what help might they need?

The study aims to talk to people to find out their views about online access. This will help to design future online access services.

You have been chosen because you belong to one of the three groups of people we are interested in: 1) healthy people aged 40-74 years, 2) people aged over 16 years with more than one long term

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health condition, and 3) their carers. We chose these three groups as there is evidence they could benefit especially from online access to records. We are aiming to recruit a minimum of 50 participants in total.

➤ **Will the outcomes of the research be published?**

We will make the findings available to health care professionals, researchers, government representatives, and software companies who can all help shape and improve future online records access services. We will also publish the results in scientific journals and inform patient groups about the results. We will send you a summary of our findings if you request this.

➤ **Who has reviewed the research project?**

The project has been reviewed by the North West - Greater Manchester NHS Research Ethics Committee (reference number: 19/NW/0293).

➤ **Who is funding the research project?**

This study has been funded by the National Institute for Health Research School for Primary Care Research (SPCR-2014-10043: Grant reference number 429).

What would my involvement be?

➤ **What would I be asked to do if I took part?**

You will be invited to take part in either a focus group or a one-to-one interview to discuss your views about online access to GP records (a focus group is a group of around 6 people who sit in the same room and have a discussion guided by a researcher). Focus groups and interviews will last up to one hour and take place at times and in locations that are convenient to those taking part. We will audio-record these discussions so that we can fully consider and review all that is said. A University of Manchester approved supplier will type up the recordings before we analyse them in our research.

We recognise that some participants may feel upset if talking about difficult experiences. The researcher will be sensitive to this and will encourage people to take a break or possibly withdraw from the activity if the discussion becomes upsetting.

There are no immediate direct benefits to taking part, but you will have the opportunity to participate in research that aims to contribute to the improvement of services providing online access to GP records, which may personally benefit you in the future.

➤ **Will I be compensated for taking part?**

To say thanks for taking part in this study we will give you a £15 shopping voucher.

➤ **What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether or not to take part. If you wish to take part please complete and return the enclosed consent form in the envelope provided. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the project once it has been anonymised as we will not be able to identify your specific data. This does not affect your data protection rights. If you decide not to take part you do not need to do anything further. We plan to audio record the interviews and focus group but you are free to decline to be recorded. Participants should be comfortable with the recording process at all times and they are free to stop the recording at any time.

Data Protection and Confidentiality

➤ **What information will you collect about me?**

In order to participate in this research project we will need to collect information that could identify you, called “personal identifiable information”. Specifically we will need to collect:

- your name
- your contact details (telephone number, address, or e-mail address)
- your postcode
- your age
- your gender
- your ethnic group
- your level of education and occupation
- if you have any medical conditions (you don’t have to tell us what they are)
- if you are a carer

The audio recordings will record voice only and will be obtained during focus groups and interviews.

➤ **Under what legal basis are you collecting this information?**

We are collecting and storing this personal identifiable information in accordance with data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is “a public interest task” and “a process necessary for research purposes”.

➤ **What are my rights in relation to the information you will collect about me?**

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you, including audio recordings. If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our Privacy Notice for Research (<http://documents.manchester.ac.uk/display.aspx?DocID=37095>).

➤ **Will my participation in the study be confidential and my personal identifiable information be protected?**

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way.

Only the study team at The University of Manchester will have access to your personal information, but they will anonymise it as soon as possible. Your name and any other identifying information will be removed and replaced with a random ID number. Only the research team at the University of Manchester will have access to the key that links this ID number to your personal information. Your consent form and contact details will be retained in a locked filing cabinet until the end of the study so that we can send you a copy of the findings.

Potential disclosures:

If, during the study, we have concerns about your safety or the safety of others, we will ask you to discuss these with your GP. If, during the study, you disclose information about any current or future illegal activities, we have a legal obligation to report this and will therefore need to inform the relevant authorities. Individuals from the University, the site where the research is taking place and regulatory authorities may need to review the study information for auditing and monitoring purposes or in the event of an incident.

Audio recordings will be held on a University of Manchester approved encrypted recording device that can only be accessed using a PIN number until the researcher returns to the University (this will normally be on the same day). Audio recordings will be transferred from the recording device to secure University of Manchester Storage as soon as possible, checked and then deleted from the recording device. Recordings will be transcribed (typed up) in a secure environment by a University of Manchester approved transcription service. Any information that could identify you or anyone else you mention will be removed from transcriptions (such as names or reference to unusual conditions). Audio recordings will be destroyed as soon as possible after transcripts have been checked for accuracy.

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

What if I have a complaint?

➤ **Contact details for complaints**

If you have a complaint that you wish to direct to members of the research team, please contact:

DR BRIAN MCMILLAN, e-mail: BRIAN.MCMILLAN@MANCHESTER.AC.UK, TEL: 0161 2757662

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If we are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 275 2674 or 275 2046 or by email to research.complaints@manchester.ac.uk.

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact

The Research Governance and Integrity Officer, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 275 2674.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the Information Commissioner's Office about complaints relating to your personal identifiable information (<https://ico.org.uk/make-a-complaint/>)
Tel: 0303 123 1113

Contact Details

If you have any queries about the study or if you are interested in taking part then please contact:

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